

Role of Reconstructive Surgery (RCS) in Improving the Quality of Life of Leprosy Afflicted Persons

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Since time immemorial, stigma has been associated with leprosy mainly due to deformity and disability which in turn affects the physical, psychological, social and economical well being of some of the leprosy afflicted persons (LAPs). To prevent and correct deformities Government of India has focused on early diagnosis and appropriate treatment. In addition government has been providing services of Reconstructive Surgery (RCS). RCS corrects the deformity and is expected to help in reducing the stigma in society and reintegrate the affected persons in to society so that they become economically self reliant and carry out their normal livelihood activities without any prejudice. As the stigma has cultural background, this study has been carried out with to assess the existing stigma level in pre RCS in society in parts of Odisha and compare with that of post RCS. The study was conducted in Sonepur district of Odisha. The sample size is the entire universe of all the 60 patients who had undergone the RCS process, during these the recent years. The methods adopted for data collection were the tools like questionnaire schedules, interview, observation, FGD and in depth case studies. Almost 86% of these Leprosy afflicted persons (LAPs) were very satisfied due to improvement in acceptance by their family, friend, relatives and society after surgery because of the correction of deformity by RCS as it enabled them to get back into normal life. The economical status improved in 8/60 (13%) after RCS, some becoming capable of earning more than Rs. 10,000/- per month after RCS. To conclude, in this settings of Sonepur (Odisha). RCS appeared to help the LAPs in improving their social acceptance thereby reducing stigma and also improving their economic status thus empowering them to lead their life as a normal human beings. There is need to enlarge and expand these studies to other parts of state/region so that the link with beliefs, type of disabilities and also type of surgery could be better understood and the knowledge generated could be applied to get optimum results.

Keywords : Leprosy, Reconstructive surgery-RCS, Stigma, Odisha, LAPs, Quality of life

Introduction

Leprosy, a disease caused by *Mycobacterium leprae*, mainly affects the skin peripheral nerves and can lead to the development of physical disabilities and potentially visible disfigurement.

Dr Hansen in 1873 first reported this bacillus to be causative organism for leprosy. Leprosy is chronic disease and occurrence of cases with disfigurement can be traced back to thousand years ago. Religious and other literature is full of

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misconceptions prevalent in various communities; important ones are that "leprosy is hereditary and not curable", "dreaded", "it is due to curse". These misconceptions of community, which are prevalent in some sections of Indian society, contribute to stigma.

Stigma was first coined by Erving Goffman in 1963 (Goffman 1963); He stated that, stigma is "blemish of identity". It manifested through rejection, isolation and shun. Stigma represents powerful and dehumanizing phenomena. As new diseases emerge, old diseases re-emerge, existing diseases remain steady, stigma inevitably will occur in a population, based on the socio-cultural reference. Stigma may not be confined to specific demographic groups; it is a cultural manifestation, specific to the population. While individuals can be immunized against specific disease, they cannot be immunized against stigma (Michele Pettit 2008). Stigma is not only associated with leprosy but also such other diseases too. It is also known that stigma attached to leprosy has been universal in all societies, unlike the stigma attached to many other social and untouchable groups which are specific to some societies. Stigma is expressed through rejection, isolation and avoidance. The stigma attached to leprosy may have serious social outcome and on several times may result in their getting ostracized by their own families and the society at large, resulting at times in breakup of families and divorce (Raju and Reddy 1995).

To prevent this discrimination towards leprosy patients, Government introduced RCS in health care facilities of leprosy. Stigma always makes the leprosy afflicted persons (LAP) to be economically more dependent on others. After introduction of Reconstructive surgery (RCS) for correcting the deformities in leprosy significant improvement in the self esteem, satisfaction levels are of these persons have been observed (John et al 2005).

This enables the patients/LAPs to lead a self sustained life as a normal human being in the society. Patients have often felt that RCS has significantly improved their performance as well as social acceptance.

Over the years efforts have continued to understand different facets/markers that relate to stigma and improve the conditions by various interventions. Sermittirong and van Brakel (2014) and Sermittirong et al (2014) have recently carried out systematic reviews of literature pertaining to concepts, causes of stigma in leprosy and methods of reducing the same. Cultural background emerges as a key factor in understanding the stigma and also in planning the interventions. Several studies have been carried out on stigma in leprosy in India and Odisha earlier. Few in-depth cases studies have been taken out to clarify the changes after RCS (John et al 2005). For the first time this present work has been undertaken in Odisha to understand the impact of Reconstructive surgery in improving the social standards of leprosy afflicted persons as measured by improvement in economy, their social acceptance and also their satisfaction levels which are important factors/features reducing stigma in society.

Materials and Methods

In this study a "Mix Method" research design was followed in which the qualitative approach is stressed upon and a Quantitative analysis using SPSS was carried out. This study was carried out in Sonepur district of Odisha in year 2012-2013 after obtaining proper Institutional Ethical Clearance. Sonepur district was selected as it is a high endemic area in the State of Odisha, with high leprosy prevalence rate of 1.39 in 2011, which was as high as 13.82 during 2001. In this district a total of 177 leprosy patients were operated upon for RCS during 2000 to 2012. Out of these 60

patients are surviving. In this study all the sixty RCS patients were enrolled as study participants. Hence, no sampling design was followed, as we have taken the entire universe of respondents in this study. In this research work, the list of patients' village wise has been collected from LEPRO Institutions in Sonapur called BOLEP which is serving leprosy patients in this area and carrying out post RCS rehabilitation.

In this study after rapport establishment, the primary data collection was carried out by the first author using social science tools like Questionnaire, Focus Group Discussion (FGD), Observation, and Interview etc. Questionnaire method was first administered, through a simple questionnaire format, for primary data collection. All the questions were open ended; Later on they were interviewed through these specific questions by door to door survey as per their convenient and availability of time. During these interactions a strong rapport was established; which enabled us to carry out the in-depth interviews. Besides these Observation was used as a major tool to find out the differences and distances maintained in the society. Focus Group Discussion tool was used extensively used to evaluate the attitude and practices prevailing in the society. Different stake holders were invited for Focus Group Discussions among the patients, paramedical staffs and other common villagers

at a time and place convenient to the participants. The statements from LAPs have been recorded in a format for pre and post RCS evaluation carried after 4-6 months of surgery when the patients have resumed their occupation; how far RCS has improved their conditions after surgery. Subjects were asked about the visible/felt benefits from surgery. The responses of the patients have been categorized into three sections i.e. very satisfied, partially satisfied and dissatisfied. In “very satisfy” section such terms identified are those who had no problem, in “partially satisfaction” they replied “about attitude through such terms as avoiding, irritating etc” but in dissatisfying section “isolation like divorce/separation” etc. were taken in to consideration.

Results

The total universe of sixty surviving Leprosy afflicted persons (LAPs) who underwent RCS were studied in the district. Pre and Post surgery views of the leprosy patients operated upon were studied. The study results were comparatively analyzed with their status which revealed details about their social relation, economical status, work related and change in profession etc. if any after RCS.

Table 1 summarises the results of satisfaction levels of patients/LAPs before surgery (Pre-RCS). About 90% Leprosy afflicted persons - LAPs had replied that they were somewhat satisfied from

Table 1 : Social Acceptance - Pre RCS

| | Sl. No | Accepted by | Very satisfied | % | Partially satisfied | % | Dissatisfied | % |
|---------|--------|---------------------------|----------------|-----|---------------------|------|--------------|------|
| Pre-RCS | 1 | Family | 0 | 0 | 54 | 90 | 6 | 10 |
| | 2 | Friends | 1 | 1.6 | 49 | 81.6 | 10 | 16.6 |
| | 3 | Relatives | 1 | 1.6 | 48 | 80 | 11 | 18.3 |
| | 4 | Society | 1 | 1.6 | 42 | 70 | 17 | 28.3 |
| | 5 | Satisfied (over all life) | 1 | 1.6 | 16 | 26.6 | 43 | 71.6 |

the treatment of their family but 10% were fully dissatisfied regarding the acceptance by family, friends, relatives, society and satisfaction upon their overall life. Approximately 80% patients were less satisfied pertaining to acceptance by others and 16.6%, 18.3% and 28.3% replied they are totally dissatisfied of acceptance by friends, relatives and society respectively. Only 1.6% people felt very satisfied from others acceptance; in contrast to 71.6% patients were dissatisfied with life before -surgery.

Post RCS results show that family acceptance and support for patients have increased, after the operation/correction of the deformity (Table 2). Almost 86% of these Leprosy afflicted persons (LAPs) were very satisfied by the acceptance of their family, friend, relatives and society, they have replied. This percentage has calculated as per the response. They stated that before RCS their dignity in the society was low but 78.3% patients showed satisfaction over all life, the

reason was "the negative comments towards me have decreased". This also implies that an amount of Self Esteem had also increased. But after surgery few patients stated they are not dissatisfied by the acceptance of their family, friends and relatives. 1.6% in family case and 3.3% by friends, relatives and community. Overall our results reveal that, the amount of progress and improvement in conditions in LAP's life after surgery as compared with pre RCS (Table 1), had increased perceptibly.

After surgery of 60 LAPs only 20(33.3%) patients had to change their profession for better economic opportunities/pursuits. That is because these persons were having some residual loss of sensation (in hand and feet) and preferred those professions which did not need much movement. Others (40) did not change their profession, because after rest and physiotherapy following surgery the affected persons felt capable of performing the functions of same old profession which they were doing earlier.

Table 2 : Social Acceptance - Post RCS

| | Sl. No | | Very satisfied | % | Partially satisfied | % | Dissatisfied | % |
|----------|--------|-------------------------|----------------|------|---------------------|------|--------------|-----|
| | | | | | | | | |
| Post-RCS | 1 | Accepted by family | 51 | 85 | 8 | 13.3 | 1 | 1.6 |
| | 2 | Accepted by friends | 52 | 86.6 | 6 | 10 | 2 | 3.3 |
| | 3 | Accepted by relatives | 52 | 86.6 | 6 | 10 | 2 | 3.3 |
| | 4 | Accepted by society | 51 | 85 | 7 | 11.6 | 2 | 3.3 |
| | 5 | Satisfied over all life | 47 | 78.3 | 12 | 20 | 1 | 1.6 |

Table 3 : Change in the Economical Status after RCS

| Income Rs/pm | Before RCS | Percentage (%) | After RCS | Percentage (%) |
|--------------|------------|----------------|-----------|----------------|
| <1000 | 21 | 35 | 13 | 21.6 |
| 1000-5000 | 36 | 60 | 40 | 66.6 |
| 6000-10000 | 3 | 5 | 5 | 8.3 |
| 10000+ | 0 | 0 | 2 | 3.3 |

While analysing the socio-economic status of the LAPs Table 3 reveals the information about change in economic status of LAPs after surgery. Before surgery 35% patients' income was below 1000/- but after surgery, this number decreased to 21.6%. This decrease in number indicates the increase in income. Similarly, in 1000 to 5000/- range it was 60% which has increased to 66.6% in post surgery. The highest number of patients are in the income group of 1000/- to 5000/- because most of the patients are belonging to farming profession. Similarly in the 6000+ range it increased to 8.3% of patients' income (6000 - 10000/-) which was only 5% before surgery. After surgery 3.3% of patient could earn above 10000.00 per month but before surgery there were no one in this group of income. After surgery economic status of these LAPs has clearly improved in many of them.

Discussion

Since ages stigma and leprosy are known to be strongly associated with each other. In various articles on leprosy, it is commonly mentioned that leprosy is a highly stigmatized disease rather in comparison to other diseases which was mainly attributed to deformities. Stigma is a complex phenomenon that has multiple causes, often linked to the cultural context in which it occurs. Cultural influences lead to enactment of many unfair laws which take lot of time for change as has happened in India (Dongre 2016). Despite this, many similarities were found in leprosy-related stigma across countries and cultures, which would facilitate the development of interventions. (Sermrittirong and van Brakel 2014). Sermrittirong et al (2014) has analysed the global efforts to reduce stigma associated with leprosy and opined that the design and implementation of IEC interventions need to be preceded by careful study of the target area

and population and should be undertaken in combination with other activities.

Reconstructive surgery has made significant contribution in improving the quality of life by correcting the deformities in leprosy. A study was carried out at the Leprosy Mission Hospital in Kolkata during 1999, to assess patients' perceptions to reconstructive surgery. Of about 300 patients operated during 1991-1997, nearly 40% had their expectations fully met, another 40% partially, and about 10% perceived benefits more than expected. Less than 5% were not satisfied. (John et al 2005). The result of the present study show after RCS in comparison to pre RCS, over 78% LAPs satisfied with social interactions/status, levels reaching 86% in social acceptance from 1.6% before surgery, this is remarkable. While there was good improvement in physical markers, in 33.3% cases sensations could not be recovered, such persons changed their profession with dignity and acceptance from society. Further post RCS the economic status improved in 13%, they could do work which was not possible before surgery. This ran parallel to increase in social acceptance which shows that RCS has a significant role in reducing stigma. The result of this study, if confirmed in larger series/ numbers, can be used as a motivational evidence to encourage LAPs to come forward for RCS. If we want to target the goal of "No deformity, No stigma", besides the current major strategy of early diagnosis and appropriate anti-leprosy & anti-reaction treatment, RCS services for already deformed individuals will have to be given due importance. Immediate priority should be to generate more evidence by expanding the study in this state and also detailed large scale studies in different states so that policy makers will feel confident of investing more in RCS.

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